

Frankly
Speaking About
Lung Cancer

Special Focus on Small Cell Lung Cancer

Presented by

**the
wellness.
community®**
cancer support, education and hope



A Welcome from The Wellness Community

Being diagnosed with small cell lung cancer can be a frightening and disheartening event. You might feel like you have few options and are no longer in control of your life. However, cancer therapy is rapidly advancing, and the number of options available to you has never been greater. It is important to remember that these treatment decisions belong to you and your physician. Working in partnership with your oncologist will strengthen the choices you make and increase satisfaction with your care.

The Wellness Community has developed this booklet to communicate some of the steps that you can take to better understand small cell lung cancer, maximize your treatment options, and make educated decisions about your therapy. This includes suggestions on how to become Patient Active in your treatment and how to partner with your health care team to help you get the best possible care.

The information in this booklet is not intended to take the place of medical care or the advice of your doctor. Indeed, this booklet was designed to help you better communicate with your health care team and better understand the information that you receive from them, to ensure that you get the personalized care that you deserve.

The Wellness Community also has another publication about lung cancer entitled *Frankly Speaking About Lung Cancer*. This comprehensive booklet can be ordered by phone at 888.793.well or downloaded at www.thewellnesscommunity.org.



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The background of the entire page is a close-up, high-resolution photograph of several green leaves. The leaves are in various shades of light green and yellow-green, with prominent veins visible. They are arranged in a way that creates a sense of depth and texture, with some leaves in the foreground being sharper than others in the background.

The Wellness Community (TWC) is an international, non-profit organization dedicated to providing free support, education and hope to people affected by cancer. Through participation in professionally-led support groups, educational workshops, and mind-body activities, people affected by cancer learn vital skills that enable them to regain control, reduce isolation and restore hope regardless of the stage of their disease. For more information, visit www.thewellnesscommunity.org.

The Wellness Community provides this information as a service. Publication of this information is not intended to take the place of medical care or the advice of your doctor. TWC strongly suggests consulting with your doctor or other health care professional about the information presented here.



Early Steps: Evaluating Your Cancer

Diagnosing Small Cell Lung Cancer

Like most cancers, small cell lung cancer is best treated when diagnosed early and accurately. The type and stage of your lung cancer will provide important insight into which treatments will be most effective.

Accurate diagnosis requires a biopsy, which involves removing a piece of the abnormal tissue and sending it to a laboratory for analysis. It is important that you receive the appropriate type of biopsy and that the tissue sample is evaluated by a lung cancer pathologist (a doctor who specializes in studying disease through the evaluation of body tissue). Another pathologist (preferably another lung cancer specialist) should review the tumor sample to confirm the diagnosis. When

you are first diagnosed with cancer, it is important to take the time to find a specialist in lung cancer with whom you feel comfortable. You may want to seek out a comprehensive cancer center or academic medical center (for example, a hospital at a large university or medical college) to ensure that you have access to a qualified doctor.

Finding a Lung Cancer Specialist

Lung cancer specialists focus on the diagnosis and treatment of lung cancer, so these specialists will typically have more experience and are more likely than a general oncologist (doctor who treats patients with cancer) to be aware of recent advances and clinical trials in lung cancer. In many cases, your primary care

physician, sometimes with the help of your insurer, will refer you to a lung cancer specialist. Lung cancer advocacy organizations can also provide you with lists of specialists in your area.

 **Getting a second opinion from a lung cancer specialist might reveal additional treatment options or give you more confidence in your decisions.**

The Importance of a Second Opinion

Getting a second opinion for your treatment may provide you with additional information or give you confidence that you are already on the right course. It does not obligate you to switch health care teams or facilities. It is important to feel confident that you are

receiving the best possible treatment for your lung cancer, so you may want to seek a second (and sometimes a third) opinion about your diagnosis and treatment plan before you begin therapy. Keep in mind that some insurance programs require second opinions, and many others will cover a second opinion if you request one. Most doctors expect and understand that patients will seek a second opinion about a cancer diagnosis. Therefore, there is no reason to be afraid that you will hurt your doctor's feelings or that he or she will treat you differently. Your doctor will appreciate that you are gathering vital information to help you make informed decisions throughout your treatment.

When Is a Second Opinion From a Lung Cancer Specialist Important?

- If you feel uncertain or unconfident about your initial diagnosis or the treatment options that you have discussed with your doctor
- If you were initially diagnosed in a small hospital or through a managed care plan that does not

treat many patients with lung cancer, and you feel that your health care team might not be familiar with all of the treatment options that can help you

- If you would like to enroll in a clinical trial (a test of new and investigational medications or treatment methods) focused on small cell lung cancer

Things to Consider When Getting a Second Opinion:

- Arrange to have a complete copy of your medical records, including original x-rays, pathology slides, laboratory results, scans, and medical reports so you can share this information with another doctor.
- Bring a friend or family member to the appointment to help take notes, ask questions, and provide support. Also, you may want to bring a tape recorder and ask the doctor if you may tape the conversation.
- Write down the questions that you would like to ask your doctor and

health care team, and bring this list along with you to your appointment so that you do not forget to ask them.

- If you receive different treatment recommendations from each doctor, discuss the pros and cons of the proposed treatment plans with the doctor with whom you feel most comfortable. Be assured that you can take the information you learned from a “second opinion doctor” back to your first doctor.
- Ask questions and discuss your medical care fully so you can make the decision that you think is best.

Many people with cancer have shared that they feel better and more in control when they have talked with another expert about their disease because they feel more confident that they have explored every possible avenue to receive the best available care.

 **Above all, once you are diagnosed with small cell lung cancer, seek out a lung cancer specialist. It could make a difference in your life and in the course of your illness.**

Here are some questions that you may want to ask your doctor or nurse:

- How much experience does this doctor have in treating cancer—specifically, lung cancer?
- Is the doctor board certified as an oncologist? Surgeon? Pulmonologist?
- How does this doctor stay up-to-date on the latest lung cancer treatments?
- Do the doctors at this clinic/hospital participate in clinical trials?
- What kind of radiation and surgical services are available at this clinic?

- Is the doctor or clinic associated with a major medical center, medical school, or National Cancer Institute-designated comprehensive cancer center?
- Does this physician or hospital accept my insurance?
- Is there an oncology nurse and/or oncology social worker that would be available for my treatment, education, and support?
- What other support services are available at this clinic for patients and their families?
- When and how can I contact my health care team?

 **Listen closely to your doctor, take notes, and be sure to ask questions if anything is not clear.**



Overview of Small Cell Lung Cancer (SCLC)

Lung cancer is the second most common cancer in men and women in the United States.¹ The most common type of lung cancer tumor is composed of relatively large cells (non-small cell lung cancer).

However, one in approximately seven people with lung cancer has small cell lung cancer (SCLC). The vast majority of people who develop SCLC either smoke tobacco products or have a history of smoking.

Small cell lung cancer is different from non-small cell lung cancer in many ways, and the cancer cells look different and behave in a different way. Small cell lung cancer cells are relatively small and egg-shaped or shaped like oat grains. These cells grow at a faster rate than normal lung cells. In fact, SCLC grows so quickly that it can spread to other parts of the body before the cancer is detected in the lungs.

Although SCLC is usually very aggressive, it generally responds to treatment with chemotherapy and radiation therapy. Unfortunately, SCLC often recurs after the initial therapy, especially, if the cancer has spread beyond the lungs, so multiple rounds of treatment may be needed to control disease symptoms and prolong survival.

Various treatment options are available, each with differing anti-cancer activity and associated side effects. Therefore, it is important for you to work closely with your family and your health care team to monitor your disease and to discuss your lifestyle and priorities so that you can work together to develop the most appropriate treatment strategy for you.

 **Small cell lung cancer is an aggressive cancer, but treatment can prolong survival and improve quality of life.**

Staging of Small Cell Lung Cancer

Your doctor will need to determine how much your tumor has grown and how far your cancer has spread, a process called “staging.” Accurate staging of SCLC is important because different stages of cancer may be more or less likely to respond to certain therapies.

“Limited-stage” SCLC means that the cancer has not spread beyond one side of a lung, and the tumor is located within a relatively small area. In contrast, “extensive-

stage” SCLC means that the lung tumor is large, involves more than one lung, or has spread to other areas of the body.

If you have been diagnosed with SCLC while it is still at the limited stage, then your chances of responding to therapy are relatively high. There is the possibility that you might achieve prolonged remission with aggressive therapy. In contrast, treatment is rarely curative in patients with extensive-stage SCLC. However, treatment can still usually improve quality of life and may prolong survival.

Survival is affected by many other things, including your age, other health conditions, and treatment decisions. Therefore, although the survival statistics for SCLC may appear discouraging, you have many options for aggressive therapy and supportive care to preserve your quality of life throughout the course of your disease.



Treatment Considerations for Newly Diagnosed Small Cell Lung Cancer

There is no one treatment for SCLC that has been proven effective for every person, so your treatment plan will be as individual as you are. Currently, treatment for SCLC involves a combination of different chemotherapy medications, which are sometimes combined with or followed by radiation therapy. Although it might seem that removal of the tumor would cure the cancer, surgery alone is usually not curative for SCLC because it is difficult to tell where the cancer has spread. Since SCLC cells have often undergone mutations (changes), they are more sensitive to chemotherapy agents and radiation than normal cells in your lungs,

so these treatments are desirable. Keep in mind that your cancer might not respond to the first attempt at therapy or might return after treatment. Even if a treatment cannot cure your disease and your disease returns, studies have shown that people with SCLC may still live longer, more comfortable lives with treatment.

🍃 **Even if treatment can not cure your cancer, it can generally help you to live a longer and more comfortable life.**

Chemotherapy

GOALS OF CHEMOTHERAPY

Chemotherapy is the treatment or control of cancer using anti-cancer drugs, highly toxic medications that destroy cancer cells by interfering with their growth or preventing their reproduction. It is a whole body treatment which means that healthy cells are often affected by the chemotherapy. Even if your cancer cannot be completely cured, chemotherapy can often provide some important benefits, which may include:

- Shrinking your tumor(s)
- Slowing the growth of cancer cells
- Preventing your cancer from spreading throughout your body
- Relieving your disease-related symptoms
- Prolonging your life

ADMINISTRATION OF CHEMOTHERAPY

Chemotherapy medications are usually administered through a needle (intravenously, or “IV”) or in tablet or liquid form (orally). Chemotherapy medications travel through your blood stream to reach the cancer cells.

 **You and your health care team will develop a chemotherapy plan that maximizes anti-cancer activity while minimizing the risk of side effects that might interfere with your quality of life.**

Chemotherapy medications damage cells that are rapidly dividing, which include cancer cells. Cancer cells are often less able to repair themselves than your normal body tissues are, so the tumors may shrink or disappear. Unfortunately, because the chemotherapy medications in your blood travel to all parts of your body, they may also affect normal cells of the body, such as blood cells, skin and hair cells, and the cells lining your mouth and digestive tract. Therefore, chemotherapy medications will often cause side effects.

The amount of medication you receive, your general health, and your age may affect the likelihood that you will experience some side effects and to what degree these will occur. Some of the side effects are short term, but other effects may be more permanent. Your health care team can provide you with additional medications or lifestyle adjustments to help decrease the severity of side effects such as digestive problems and infections. Therefore, you should track and discuss with your health care team all of the side effects you may encounter. [For more information on side-effect management, please refer to the general *Frankly Speaking About Lung Cancer* booklet or go online at www.thewellnesscommunity.org].

Chemotherapy programs are tailored to the needs of each person. You and your doctor will develop a treatment plan appropriate for your stage of small cell lung cancer and your general state of health. It is important to have an open and direct conversation with your doctor about your goals for treatment, weighing both the potential effectiveness of the treatments and their potential side effects.

Table I (on the following page) is a summary of chemotherapy agents that are currently used to treat patients with newly diagnosed SCLC or SCLC that has recurred after treatment. Although some agents have not received approval from the US Food and Drug Administration for use in patients with SCLC, they may be reasonable alternatives if you are unable to receive the standard therapy.

Table 1. POTENTIAL CHEMOTHERAPY TREATMENTS FOR SCLC

Limited Stage	Extensive Stage	Recurrent SCLC
■ EC: etoposide + cisplatin + chest radiation therapy	■ EP or EC: etoposide + cisplatin or carboplatin	■ Topotecan
■ Other drugs in clinical trials	■ CAV: cyclophosphamide doxorubicin + vincristine	■ Other drugs in clinical trials
	■ CAE: cyclophosphamide doxorubicin + etoposide	
	■ ICE: ifosfamide + carboplatin + etoposide	
	■ Cisplatin + irinotecan	
	■ Other drugs in clinical trials	

CLINICAL TRIALS

You and your health care team will likely discuss current treatment options, including the possibility of a clinical trial that might be right for you. A clinical trial may give you the opportunity to receive the most advanced treatment available today, so participation in clinical trials is sometimes encouraged. For more information about clinical trials, call the National Cancer Institute at 1-800-4CANCER, or review their website at www.cancer.gov.

TREATMENT OF NEWLY DIAGNOSED, LIMITED-STAGE SCLC

The most common therapy for limited-stage SCLC is a combination of radiation therapy to the chest and chemotherapy. The most common combination of chemotherapy plus radiation therapy is cisplatin and etoposide, with radiation therapy to the chest. Vincristine is sometimes added to this combination. Various other regimens, such as single-agent topotecan (topotecan administered alone), single-agent paclitaxel, and several combination chemotherapy regimens, are currently being investigated in clinical trials for the treatment of limited-stage SCLC.

CHEMOTHERAPY FOR NEWLY DIAGNOSED, EXTENSIVE-STAGE SCLC

The most common treatment for extensive-stage SCLC is chemotherapy without additional radiation therapy. Radiation therapy is usually not beneficial in people with extensive-stage SCLC because the disease has spread to other organs. Furthermore, because extensive-stage SCLC often relapses, additional rounds of treatment may be required, and the permanent effects of chemotherapy and radiation therapy may limit later treatment options. Therefore, the choice of which initial treatment plan to use for extensive-stage SCLC will involve a balance between the anti-cancer activity of the therapy and the potential for permanent side effects.

The most commonly used treatments for extensive-stage SCLC combine etoposide with either cisplatin or carboplatin.

Other options include

- cisplatin + irinotecan
- cyclophosphamide + doxorubicin + vincristine

- cyclophosphamide + doxorubicin + etoposide
- ifosfamide + carboplatin + etoposide

Other new or less-proven treatments include:

- cyclophosphamide + etoposide + vincristine
- single-agent etoposide
- single-agent paclitaxel
- single-agent topotecan

Irinotecan has not been approved for use in extensive-stage SCLC, but is often used because it generated promising results in combination with cisplatin in clinical trials.⁴ Other therapeutic regimens are also under investigation in clinical trials.

SPECIAL CONSIDERATIONS FOR SELECTING A FIRST-LINE TREATMENT REGIMEN

People with diabetes, liver or kidney disease, high blood pressure, and advanced age are at risk for experiencing more severe side effects during chemotherapy. Your health care team will also consider your “performance status,” which measures how you are able to work

and perform basic life functions. People with poor performance status are often at higher risk for side effects, so alternate treatments may be necessary. Another important consideration is that some chemotherapy agents cannot be administered while you are receiving other medications, such as medications for fungal or viral infections, psychological conditions, or metabolic diseases.

Your lung cancer specialist will also determine your risk for “cumulative toxicity” before administering first line chemotherapy, especially if there is risk for recurrent small cell lung cancer.

 **Standard treatment regimens are well established and generally active, but other treatments might be safer for some people.**

Cumulative toxicity refers to side effects of treatment that may build up and become progressively worse over time. Some chemotherapy agents can damage vital organs, which in turn can affect how well your internal organs (for example, digestive system, liver, kidneys), nerves, or bone marrow work. Your doctor should carefully consider this risk with you.

Radiation

GOALS OF RADIATION THERAPY

Many people with SCLC need radiation therapy at some time during their illness. Radiation therapy combined with chemotherapy can cure some patients who have limited disease and may lengthen survival and improve quality of life in others by providing symptom relief (palliation) when a cure is not possible. Certain cancer specialists called radiation oncologists provide this specialized treatment.

There are many possible goals of radiation therapy:

- Increase the response of localized tumors to chemotherapy
- Reduce the risk of recurrence in patients whose disease has responded to chemotherapy
- Prevent cancer cells that may have spread from developing into tumors
- Relieve your disease-related symptoms such as bone pain
- Prolong your life

COMBINING CHEMOTHERAPY WITH RADIATION THERAPY

The combination of chemotherapy and radiation therapy can result in very potent anti-cancer effects. However, combining therapies might increase your risk of side effects, especially if you have risk factors such as other illnesses or a decrease in your ability to generate new blood cells because of your age or prior therapy for your cancer.

 **Radiation therapy is often used to minimize the risk of disease recurrence or to reduce cancer-associated symptoms.**

REDUCING THE RISK OF RECURRENCE IN PEOPLE WHOSE CANCER RESPONDS TO CHEMOTHERAPY

Small cell lung cancer often returns, even in people whose cancer is no longer detectable after initial therapy. If the tumor spreads to the brain, it may have especially negative effects on survival. Therefore, patients who respond to therapy are often offered the option of “prophylactic cranial irradiation (PCI)”. This means radiation therapy of the head to prevent any SCLC cells that may have reached your brain from growing into tumors after you stop receiving chemotherapy. You may want to discuss the relative benefits and possible side effects of this treatment with your health care team.

RELIEF OF CANCER-RELATED SYMPTOMS

Palliative (to relieve symptoms) radiation therapy to sites where the cancer has spread (metastasized) may reduce cancer-associated symptoms, especially in the brain, spine, or bone. A symptom that often develops in people with SCLC is shortness of breath because of tumor expansion into the lungs’ air passages. Radiation therapy may be effective in relieving this symptom in some people. However, other treatments may be available that have a lower risk of side effects, and you should discuss possible symptom management options with your health care team.

PROLONGING SURVIVAL

Even if radiation therapy cannot completely cure your cancer, it can often slow the growth of your tumor. Therefore, similarly to chemotherapy, radiation therapy may prolong survival in people whose cancer cannot be cured.



Resistant or Recurrent Small Cell Lung Cancer

If your SCLC does not respond to initial therapy it is considered “resistant.” If the disease responds at first but then returns less than three months after treatment, it is considered “refractory.” “Recurrent” disease is any SCLC that returns within two years of successful treatment. SCLC that returns more than two years after successful treatment generally responds to therapy in a way similar to that of newly diagnosed cancer (please refer to section on **Treatment Considerations for Newly Diagnosed Small Cell Lung Cancer**).

The goals of therapy for patients with resistant or recurrent SCLC are generally more focused on quality of life and symptom management than on cure. There may even be a question about whether to continue treatment at this point.

However, treatment for resistant or recurrent SCLC may prolong your life and reduce your disease symptoms. Your chance of side effects may be higher than it is during initial therapy but you will already be aware of the possible side effects from your initial treatment and can compare your prior experiences to those of the disease symptoms you may be experiencing. At this stage you might also be less able to tolerate chemotherapy, unless it is a treatment with milder side effects.

Your health care team will discuss important health considerations and which options are available, including ongoing clinical trials. For some patients, clinical trials may provide the best treatment options for recurrent SCLC.

Chemotherapy for Resistant or Recurrent Small Cell Lung Cancer

The National Cancer Institute (2004) states that while no single chemotherapy regimen should be considered standard, several treatment options have shown promise when SCLC continues to grow during or after initial chemotherapy. Only topotecan has received approval from the FDA for use as single-agent therapy in patients with recurrent SCLC.⁵ Other treatment regimens that may be considered include cyclophosphamide + doxorubicin + vincristine; single-agent oral etoposide; etoposide + cisplatin; and single-agent paclitaxel. Each regimen has benefits and limitations.

For patients with recurrent SCLC, re-treatment with the same regimen that was used successfully for first-line therapy may be a good option. Re-treatment may, however, increase the likelihood of

 **Each treatment option for recurrent or resistant SCLC has its own benefits and limitations, and you should discuss these with your health care team.**

cumulative organ damage, as discussed previously, so the effects of your disease and prior exposure to chemotherapy agents may limit your options.

For elderly patients or patients with poor performance status, only topotecan has demonstrated safety and activity in clinical trials.^{6,7} Alternatives to the standard topotecan administration schedule (five days of treatment each month) are currently being investigated to determine whether side effects in heavily pretreated

patients can be minimized. For example, although the standard topotecan regimen is generally well tolerated, its temporary effects on white blood cells can be severe and cause fever or infections. In contrast, alternate schedules such as weekly administration are associated with a lower risk of these events.⁸ Alternate administration schedules for chemotherapy agents, such as once-weekly topotecan and once-weekly paclitaxel, are currently being investigated in clinical trials.

Because each patient's cancer and situation are very different, there are a variety of chemotherapy drugs that your oncologist may recommend to treat recurrent SCLC. It is important to take into account your personal goals for treatment and how you will manage potential side effects.





Managing Side Effects and Improving Quality of Life

Most cancer treatments have some associated side effects. The likelihood of your experiencing these side effects is influenced by the dosage and schedule of the medication you receive, your prior treatment history, general health, age, and performance status. Because some side effects are relatively common, treatment strategies have already been developed to make you more comfortable during therapy. Common side effects and treatment strategies that have been developed for these side effects are summarized in Table 2. Although many symptoms can be treated with over-the-

 **Many cancer symptoms and therapy side effects can be controlled or reduced with medication and/or lifestyle changes.**

counter medications, it is important to discuss all medications with your health care team ahead of time. It may be unsafe to take some over-the-counter medications during treatment with some chemotherapy drugs.

Table 2. COMMON SIDE EFFECTS AND THEIR MANAGEMENT*

Side effect(s)	Treatments that may induce these side effects	Common management strategies
Nausea and vomiting	<u>Carboplatin</u> , <u>cisplatin</u> , cyclophosphamide, doxorubicin, etoposide; irinotecan, gemcitabine, ifosfamide, paclitaxel, topotecan, vinorelbine	Antiemetic medications; avoid strong perfumes; get plenty of fresh air; eat many small meals throughout the day
Allergic reaction to chemotherapy	Cisplatin, carboplatin, cyclophosphamide, doxorubicin, etoposide, gemcitabine, irinotecan, paclitaxel	Discontinue therapy; steroidal and nonsteroidal antihistamines
Anemia (↓ energy and stamina; pale skin)	Cisplatin, carboplatin, etoposide, gemcitabine, <u>topotecan</u> , vinorelbine	Red blood cell transfusions; treatment with red blood cell growth factor (Erythropoietin)
Decreases in white blood cells (↑ risk of infections)	<u>Cisplatin</u> , carboplatin, cyclophosphamide, doxorubicin, <u>etoposide</u> , <u>gemcitabine</u> , <u>irinotecan</u> , paclitaxel, <u>topotecan</u> , vinorelbine	Avoid contact with people who have infections; clean all wounds and apply antibiotics; treatment with white blood cell growth factor (Granulocyte colony-stimulating factor)
Decreased blood clotting (↑ risk of bleeding)	Cisplatin, <u>carboplatin</u> , doxorubicin, etoposide, gemcitabine, <u>topotecan</u>	Avoid scrapes and bruises (Platelet transfusion)
Pain or loss of feeling in hands and feet (neuropathy)	Cisplatin, carboplatin, doxorubicin, gemcitabine, ifosfamide, paclitaxel, docetaxel, vinorelbine	Discontinue medication or reduce dosage
Effects on heart function	<u>Doxorubicin</u> , cyclophosphamide	Discontinue medication and contact doctor immediately
Diarrhea	Etoposide, <u>irinotecan</u> , topotecan	Eat starchy and non-spicy foods (pale foods like bread and rice); treatment with antidiarrheal medicines

Constipation	Topotecan, vinorelbine	Eat high-fiber foods; drink plenty of water (Laxatives)
Hearing loss and decreased color vision	Cisplatin	Discontinue if severe; vision usually returns after you stop taking cisplatin; hearing usually does not
Confusion; depression (central nervous system effects)	Ifosfamide	Discontinue medication or reduce dosage
Loss of appetite	Carboplatin, cyclophosphamide, etoposide, topotecan	Eat small meals many times a day; eat foods with a high nutritional value
Blood in urine (possible kidney or bladder damage)	<u>Cisplatin, cyclophosphamide, ifosfamide, gemcitabine</u>	Contact your doctor immediately; drink plenty of water
Flu-like symptoms (fever, body aches, nausea, fatigue)	Gemcitabine	Analgesics for fever and pain (Acetaminophen, ibuprofen, or naproxyn)
Rash	Gemcitabine, topotecan	Apply skin lotions; dose reduction
Swelling of the feet and ankles (edema)	Gemcitabine	Elevate your legs when you rest; drink plenty of water
Changes in skin and decreased wound healing	Most chemotherapy agents	Avoid direct sunlight and wear sunscreen; avoid scrapes and bruises; keep wounds clean and use antibiotic creams
Note: Chemotherapy agents that are <u>underlined</u> may cause severe levels of the particular side effect. *Information is from chemotherapy agent product information and Bast RC Jr, et al.⁹		

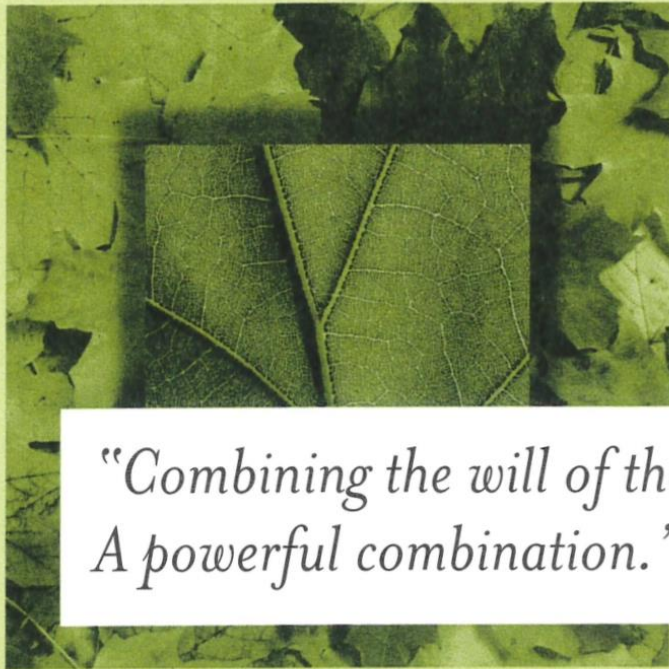
Cancer-Related Symptoms

If your treatment is unlikely to be curative, an important consideration is the level of symptoms that you are experiencing from your SCLC. For most symptoms, anti-cancer medications are the most effective management strategy. However, some of these treatments may cause more symptoms than they relieve, especially in “high-risk” patients (as discussed previously). A decision to not receive

anti-cancer therapy at any point during the course of your disease does not mean that you are giving up hope or that you will not be able to receive anti-cancer therapy later on. It only means that the risks of chemotherapy outweigh the potential benefits at that point in the course of your disease. Some examples of SCLC symptoms and management strategies are described in Table 3.

Table 3. POSSIBLE SYMPTOMS AND MANAGEMENT STRATEGIES^{3,9}

Symptom	Explanation	Treatment
Fatigue (getting tired easily)	Cancer growth can use up your body's energy	Chemotherapy or radiation therapy to slow tumor growth; plenty of rest; and eating well
	Anemia (decreased supply of red blood cells from damage to the bone marrow)	Vitamin and mineral supplements; red blood cell transfusion; growth factor treatment (erythropoietin)
Cough (sometimes with blood); wheezing; hoarseness	Lungs are damaged by tumor growth	Chemotherapy or radiation therapy to slow tumor growth; cough medicine; lozenges
Loss of feeling or shaking in hands and feet	Cancer and imbalances in your body chemistry or immune system may be affecting your nerves	Chemotherapy or radiation therapy to slow tumor growth; treatment for possible autoimmune dysfunction
Pain	Tumor growth can press on nerves or cause damage to surrounding tissue, especially in bone	Analgesics (acetaminophen, ibuprofen) or prescription pain relievers For bone pain: radiation therapy or bisphosphonates
Shortness of breath	Cancer growth into airways; decreased lung function	Chemotherapy or radiation therapy to slow tumor growth; surgery to remove tumor (if localized); oxygen
Nausea and vomiting; loss of appetite	Physical and emotional stress may interfere with digestion; Tumors can grow and press on your digestive organs	Antiemetic medications; avoid strong perfumes; get plenty of fresh air; eat many small meals throughout the day



The Wellness Community's Patient Active Concept

*"Combining the will of the patient with the skill of the physician—
A powerful combination."*

—Harold H. Benjamin, PhD, Founder, The Wellness Community

The Patient Active Concept defines a series of actions, behaviors, and attitudes that people with cancer and their loved ones use to improve their quality of life but also to enhance the possibility of recovery. First and foremost, being Patient Active is about feeling and acting empowered. It is about your ACTIVE PARTICIPATION in the choices you and your health care team make about treatment. Choosing to be Patient Active is not about one monumental decision, but rather a series of small, incremental choices. These choices help you regain a sense of control over your treatment and in your life in general.

Because research has shown that there are three psychological and emotional stresses that many people with cancer face—**unwanted aloneness, loss of control and loss of hope**—taking steps to gain information, seek support and learn how to improve your quality of life is critical for people with cancer.

There is no right or wrong way to be Patient Active since you decide what is best for you. You can make informed decisions about small cell lung cancer treatment as well as the management of side effects and your general health and well-being, including relationships with others and coping with the stress that cancer brings into our lives.



Actions You Can Take in the Fight for Recovery from Lung Cancer

Make Plans for the Future

You may find it helpful to set short-term goals and make long-range plans. If you aren't making plans for the future, you may subconsciously believe that there is no future. Making plans in and of itself can be a pleasant and positive experience.

Support May Come From Unexpected Places

Some of your friends and family may act differently toward you after the diagnosis. They need your help. Tell them openly how you want them to treat you. Most of them will respond positively. Some people may

not be able to overcome their own fears and anxiety about your illness. The people that you least expect to be of help may emerge and surprise you as your greatest support.

Don't Be a Loner

Some people with cancer find that they are choosing to be alone because they feel so detached from the world they once knew before they were ill. If you have stopped doing what you enjoyed before the diagnosis, and you can still do it—start it again. Tell your friends what you are feeling. Ask them to help you not isolate yourself. Give yourself permission to be alone when you need to be and learn to identify when you need to be with others.

Regain and Maintain as Much Control of Your Life as Is Reasonable

Many people with cancer feel like they have to give up some control to health professionals, family and friends, and even the disease itself. The health care system sometimes makes it difficult for you to feel in charge of your care. Try not to give up more control than you want or need to. Make a list of the things you feel you have less control over, and decide what to take back. The desire to regain control is a normal, healthy response to a threat or stressor. Find even the simplest things that help enhance the feeling of being in control.

Utilize the Relaxation Response

The Relaxation Response describes a method for achieving a physical feeling of peacefulness and calm. This is important to people with cancer because a relaxed state of mind and body has been shown to enhance the immune system for a period of time. Examples are breathing, meditation, and visualization. Stress-reduction techniques take very little time, are easy to do, and almost always leave you feeling more calm and relaxed.

Become Partners With Your Physician

Some people want to just be given medical directions from their physician. Others want to be an integral part of the decision-making process. Most physicians want to act in any capacity that is in the best interest of their patients. Discuss this matter with your physician, along with your treatment goals, and create relationship that feels comfortable.

It Is Not Necessary to Give Up Intimacy and Affection

Physical closeness and intimacy are an essential part of our lives. Although you may be experiencing physical or emotional symptoms that make intimacy difficult, remember that the solution to solving problems is communication and openness between you and your partner.

Hope Can Take Many Forms

There is no type of cancer that does not have some recovery rate. Hope, therefore, is not only desirable, but in many situations quite reasonable. Hope can also take other forms. If the hope of physical recovery becomes unlikely, then one can hope for spiritual or emotional recovery. Regardless, people who find something that gives them hope often do better emotionally with whatever challenges lie ahead.

Seek Emotional Support

We are, by nature, social human beings connected to other people both on a personal level and as part of a greater community. Getting help and seeking support should be as integral to your cancer treatment as chemotherapy, radiation, or surgery. Those who are able to connect with others in a safe, constructive way, such as at The Wellness Community or through other cancer support organizations, generally note an improvement in their quality of life during cancer treatment and beyond. Emotional support from family, friends, health professionals, fellow cancer patients, spiritual or church relationships, and other social networks can significantly enhance regaining a sense of control, feeling less alone, and finding hope to sustain you throughout the cancer experience and beyond.

Participate in Support Groups

Support groups provide a way to meet other people with cancer and/or their family members to share concerns and coping strategies. They are not psychotherapy sessions. Rather, they provide opportunities for people in similar situations to share information about ways to handle problems, family concerns, talking with doctors, etc. Being part of a support group can decrease the sense of isolation that people affected by lung cancer often experience. No matter how the group is organized, the basic goal is to help cancer patients and their family members feel less isolated and learn more about dealing with cancer-related problems.

People who participate in support groups at The Wellness Community have found that they are better able to: 1) make active choices in their recovery; 2) make changes in their lives that they think are important; 3) partner with their physician; 4) access valuable resources; and 5) develop a new attitude towards the illness.

Locating Support:

- The Wellness Community offers weekly support groups for people with all types of cancer and separate support groups for caregivers. Some facilities offer a monthly Lung Cancer Networking Group. Contact The Wellness Community—National at (888) 793-WELL or www.thewellnesscommunity.org to find a Wellness Community near where you live or work, or to access a real-time online support group.
- CancerCare, Inc, offers face-to-face lung cancer support groups in the New York area, and telephone support groups and online chat rooms for people with lung cancer nationwide. They can be contacted at (800) 813-HOPE or at www.cancercare.org.

- ALCASE (the Alliance for Lung Cancer Advocacy, Support and Education) offers a Phone Buddy program to help you connect with other lung cancer patients or caregivers. Call toll free 1-800-298-2436 or visit www.alcase.org.
- The American Cancer Society also offers recommendations for groups in your area.
- You can ask your doctor, nurse, or social worker about other hospital or community-sponsored groups near you.

Individual or Family Counseling

Counseling can help people with cancer and their families learn more effective ways to communicate about the illness, cope better with the normal feelings and reactions to lung cancer, address changes in roles and family routines that may

result from a chronic illness in the family, learn new ways to solve problems, learn methods of reducing stress, and relieve some of the physical and emotional side effects of cancer and cancer therapy.

- Ask whether the hospital or treatment center provides counseling services for people with cancer and their families
- Ask the doctor, nurse, and/or social worker for a referral for outside individual or family counseling, and make sure you find someone experienced in dealing with the particular challenges facing people affected by cancer
- Talk to your spiritual counselor about counseling services
- Contact community agencies that provide counseling services or referral services for professional mental health organizations





Resources

The Wellness Community

1-888-793-well

www.thewellnesscommunity.org

ALCASE

1-800-298-2436

www.alcase.org

CancerCare

1-800-813-HOPE

www.cancercares.org

National Cancer Institute

1-800-4CANCER

www.cancer.gov

Lung Cancer Online

www.lungcancer.org

People Living With Cancer

www.plwc.org

National Coalition for Cancer
Survivorship

1-877-NCCS-YES

www.canceradvocacy.org

National Comprehensive Cancer
Network

Lung Cancer Guidelines

1-888-909-NCCN

www.nccn.org



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Notes



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